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Research Article

Fatigue after Stroke: The Patient's Perspective

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Background. Fatigue after stroke is common and distressing to patients. **Aims.** Our aims were to explore patients' perceptions of post-stroke fatigue, including the causes of fatigue and the factors that alleviate fatigue, in a mixed methods study. **Results.** We interviewed 15 patients who had had a stroke and were inpatients on stroke rehabilitation wards. A substantial proportion of patients reported that their fatigue started at the time of their stroke. Various different factors were reported to improve fatigue, including exercise, good sleep, rehabilitation and rest. Fatigue influences patients' sense of "control" after their stroke. **Conclusion.** Our results are consistent with the possibility that poststroke fatigue might be triggered by factors that occur at the time of the stroke (e.g., the stroke lesion itself, or admission to hospital) and then exacerbated by poor sleep and boredom. These factors should be considered when developing complex interventions to improve post-stroke fatigue.

1. Introduction

Fatigue is defined as a feeling of lack of energy, weariness, and aversion to effort [1]. Fatigue is common after stroke [2] with a prevalence ranging from 16% to 72% [2–7] depending on the population studied and whether patients with mood disorders are included or excluded. One recent large study demonstrated that fatigue after stroke was associated with lower self-reported mood, was more common in women, and increased with age, but together these factors explain only about 30% of the variance in fatigue [8]. Other small studies have demonstrated associations with systemic inflammation [9], reduced physical fitness [10], and "a locus of control directed towards powerful others" [11]. In a population-based study of minor ischaemic stroke and TIA, fatigue was more common in stroke than TIA [12]. Because the stroke patients had little or no motor deficit, the authors suggested that their excess of fatigue compared with TIA patients might be attributable to central mechanisms, rather than the result of increased physical effort required after stroke [12]. Early work suggested an association with brain stem strokes [2], though this has not been confirmed by more recent studies. Recently, a very small study suggested that "central" fatigue might be associated with mood disorders

and that "exertional" fatigue is associated with impaired physical fitness [13].

Many stroke survivors do not make a complete recovery from their stroke and are left with residual neurological problems and other long-term consequences such as depression, reduced physical fitness, impaired cognition, and an increased risk of falls. Given the plethora of after stroke symptoms, an important question is whether fatigue actually matters to patients. The available literature suggests that fatigue is perceived as a major problem after stroke. For example, in a postal survey of 88 stroke survivors, 68% reported that they had fatigue, and 40% reported that fatigue was their worst or one of their worst symptoms [4]. Fatigue affected functioning in physical and psychological domains [4]. In another study of 90 stroke survivors at least one year post-stroke, 50% of participants indicated that fatigue was their main complaint [14]. Furthermore, fatigue in stroke patients has been linked to shorter survival and a higher risk of institutionalization [5].

Given the large burden of fatigue after stroke and its possible adverse impact on survival, further research is crucial to better understand its aetiology, in order to develop new treatments. The patient's perspective is essential given the subjective nature of fatigue, and qualitative research

TABLE 1: Characteristics of participants.

Characteristic	Participants (<i>n</i> = 15)
Age (mean \pm SD)	72.3 \pm 11.5
Gender (% Female)	11 (73%)
Stroke Severity (NIHSS) (mean \pm SD)	3.9 \pm 3.5
Fatigue Assessment score (mean \pm SD)	24.8 \pm 6.5
Time since stroke in weeks (mean \pm SD)	13.4 \pm 9.4
Localization (%)	
Right hemisphere	7 (47%)
Left hemisphere	6 (40%)
Other	2 (13%)
OCSP syndrome type (%)	
Posterior circulation	3 (20%)
Total anterior circulation	5 (33%)
Partial anterior circulation	6 (40%)
Lacunar syndrome	1 (7%)
Pathological subtype	
Ischaemic	14 (93%)
Haemorrhagic	1 (7%)
Comorbid conditions (%)	
Hypertension	9 (60%)
Diabetes	3 (20%)
Previous stroke	1 (7%)
Arthritis	1 (7%)
Thyroid disease	2 (13%)
Medications (%)	
β -blockers	3 (20%)
Antiplatelets	10 (67%)
Statins	12 (80%)
Antihypertensives	9 (60%)
Mobility (%)	
Walking	73
Nonwalking	26

methods are ideal for in-depth exploration of the patient's perspectives. One small qualitative study recruiting 19 stroke survivors to three focus groups explored stroke survivors' views of fatigue after stroke [15]. This study reported that stroke survivors felt unprepared for the fatigue phenomenon and struggled to adapt, with fatigue having a debilitating influence upon daily occupational performance and roles, including social participation, return to work, driving, reading, and sleeping. The participants indicated that exercise (such as walking and water aerobics) and use of assistive technology were helpful strategies in reducing fatigue [15].

Our aim was to explore, using mixed qualitative and quantitative methods, patients' perceptions of post-stroke fatigue, including its aetiology, and its exacerbating, and relieving factors, with a view to developing new treatments.

2. Methods

The study was approved by Lothian Research Ethics Committee. We performed a mixed-qualitative and quantitative

interview study recruiting patients from inpatient stroke rehabilitation wards in Edinburgh (July–September 2009). To be approached by the researcher for inclusion into the study, patients had to have suffered a stroke at least one month prior to interview, and the nurses had to report that they were suffering from fatigue (based on their observations of the patient and patients' own reports of fatigue). Those with severe dysphasia, confusion and those who were medically unstable due to another medical condition were not eligible. Eligible patients were given a patient information sheet and those who consented were included in the study.

The researcher (VB) administered the National Institute of Stroke Scale (NIHSS) [16], diagnostic criteria for post-stroke fatigue [17], and the Fatigue Assessment Scale (FAS) [18] to assess fatigue severity. To fulfil diagnostic criteria for post-stroke fatigue, patients had to have fatigue for more than 50% of waking hours, and the fatigue had to be clinically significant, that is, interfere with activities of daily living [17]. The researcher then performed a semistructured interview, with both "closed" and "open" questions, to explore patients' beliefs about the aetiology of their fatigue, and its exacerbating and relieving factors (see Figure 4). Patient responses were explored in more detail by the researcher, and emerging concepts were identified. The researcher recorded patient responses on paper data collection forms, and then used a five-step thematic framework approach [19] to analyse the qualitative data. The first step involved familiarisation with the data to list key themes that arose. The second step involves drawing out all the main concepts, themes, and issues in relation to aims of the study and patient responses. In step 3 all the data were reviewed and the thematic framework applied; codes were assigned to the relevant themes. In step 4, the data were then rearranged according to various themes. Finally, step 5 involves mapping and interpreting the data, and finding links between themes keeping in mind the aims of the study.

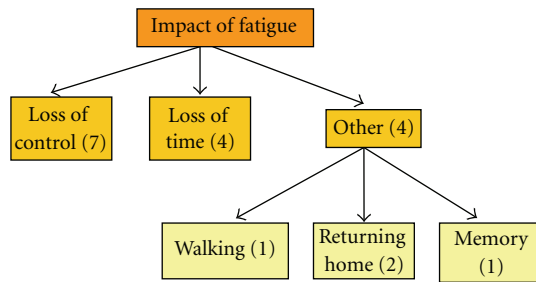
3. Results

All patients were recruited during their hospital admission because of their stroke. Twenty-three patients were identified by nursing staff as having fatigue. One could not hear well enough to participate and four patients felt too tired to speak to researcher. After reading the study information sheet, a further three patients did not think the study applied to them as they were not experiencing fatigue, leaving fifteen patients who participated in the study.

The characteristics of the 15 participants are shown in Table 1. All 15 met our case definition for post-stroke fatigue. The mean FAS score was 25 [SD 6.5].

3.1. Nature of Fatigue after Stroke. Six (40%) patients reported feeling fatigued before the stroke but all six patients said that their fatigue after their stroke was a different type of fatigue from the fatigue that they had experienced prior to their stroke.

Patients described their post-stroke fatigue to be "a tiredness in the muscles" (9/15, 60%), "a general feeling of tiredness" (10/15, 67%), or "mental tiredness" (5/15, 33%).



The numbers in brackets are the number of patients who had the boxed opinion

FIGURE 1: Impact of fatigue.

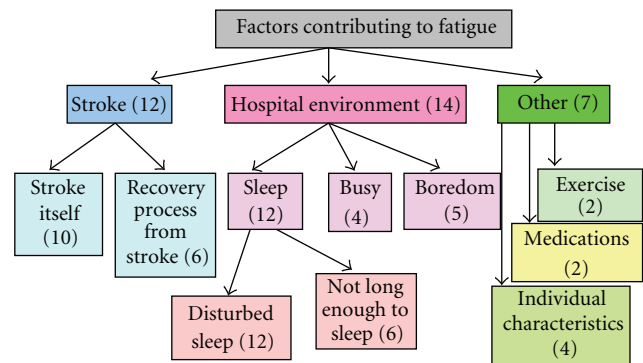
3.2. Aetiology of Fatigue, Exacerbating, and Relieving Factors. Twelve (80%) patients felt the fatigue was caused by the stroke itself or brain recovery, 14 (93%) patients felt hospital environment contributed, and 5 (33%) felt that boredom was a contributor. Twelve (80%) had been woken at least once during the night as a result of disturbance on the ward and 6 (40%) complained that not being given long enough to sleep in general (being woken very early for washing and breakfast) also contributed to fatigue.

Only three patients (20%) reported that meal times made their fatigue worse and five (33%) patients felt that medications made their fatigue worse. There was no particular time of day that patients felt most fatigued: five (33%) patients reported that they were most severely affected in the morning, six (40%) noticed fatigue being worst in afternoon, three (20%) reported that their fatigue was constant throughout the day, and one (7%) patient said that the fatigue was worst in the evening. Five (33%) reported visiting times as aggravating their fatigue, nine (60%) patients felt that exercise and rehabilitation helped fatigue, and 14 (93%) found sleep beneficial.

Qualitative analysis identified several themes and sub-themes. The main impact of fatigue was a sense of loss of control (7 patients), loss of time (4 patients), adverse effect on walking (one patient), returning home (2 patients), and memory (one patient) (Figure 1). Contributing factors to fatigue include the stroke as a central process as well as recovery and hospital environment (in particular sleep) (Figure 2). Interventions that patients felt would help included mental stimulation, exercise, sleep, and more activities on the ward (Figure 3). Environmental suggestions for improving fatigue included fresh air, returning home, more staff, and better access to facilities such as television, internet, and ward activities. Four (27%) patients felt that better organisation on the ward would help their fatigue; subthemes included more staff, a more relaxed environment, and increased staff availability to carry out activities. Another subtheme suggested by one patient was arranging bays so that patients with less severe dysphasia were grouped together so that they could converse with one another.

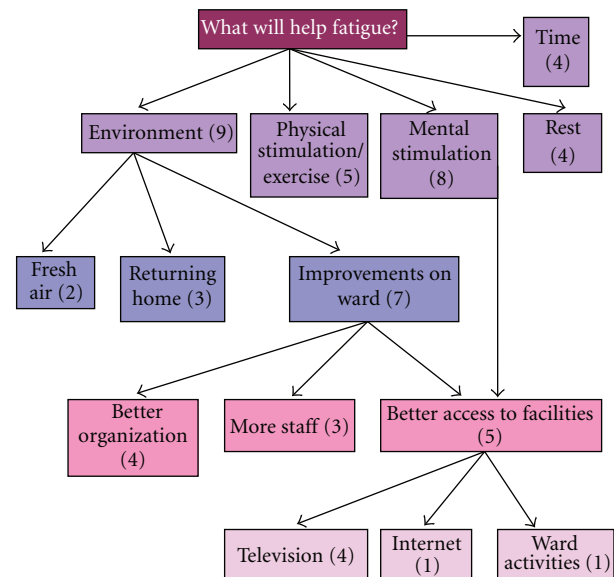
4. Discussion

There is very little information in the literature about patient's perception of the causes of fatigue after stroke, or



The numbers in brackets are the number of patients who had the boxed opinion

FIGURE 2: Factors contributing to and exacerbating fatigue.



The numbers in brackets are the number of patients who had the boxed opinion

FIGURE 3: Factors that might help fatigue.

about the factors that might exacerbate or improve fatigue. Intriguingly, a substantial proportion of patients felt that their fatigue started at the time of their stroke, and that post-stroke fatigue was different in phenomenology than any prestroke fatigue that they had experienced. This observation would be consistent with the idea of a "central" neurological cause of post-stroke fatigue [12]. Some patients also felt that fatigue was part of the normal recovery process from stroke. Exercise was reported by some patients to improve fatigue, confirming the findings of a previous small qualitative study, but some patients reported that rest improved fatigue [15]. Most patients reported that sleep improved fatigue, and so it is concerning that the majority of the patients reported disturbed sleep in hospital. The majority of patients felt that the ward environment was a major contributor to fatigue and recommended simple ward changes such as better access to television, internet, and activities.

Fatigue before stroke.

Did you feel fatigued before your stroke?

If so, what was it like? Is fatigue NOW similar or different to what you had before?

Characteristics of fatigue now.

Is it a ☐ tiredness in your muscles (patient can choose >1)
☐ general feeling of tiredness
☐ mental fatigue

Is there any time of day you feel more fatigued?

If YES: Is it morning, afternoon or evening?

How long does your fatigue last in a 24 hr period? _____ hrs

Change in fatigue over time: Is it getting better, staying the same, or getting worse?

Sleep

On average, how many hours of sleep do you get a night?

On average, how many times a night do you get woken by disturbance on the ward?

Is there anything else that wakes you?

Do you nap during the day? If so, how many hours for?

Precipitating and relieving factors (take note of any relevant comments made by patients)

Using scale:

Strongly agree Agree Neutral Disagree Strongly disagree

Do you find that exercise makes you feel less fatigued?

Do you find that doing rehabilitation makes you feel less fatigued?

(explain to patient what is meant by rehabilitation)

Do you find that sleeping makes you feel less fatigued?

Do you feel that medication makes you feel less fatigued?

Do you feel that your fatigue is worse at or after meal times?

Do you feel more fatigued at or after visiting times?

Do you have visitors:

- ☐ more than once a day
- ☐ once a day,
- ☐ every few days,
- ☐ not very often.

Do you think the staff do enough to help you?

- is there anything else they could do to help?

Do you find that resting makes the fatigue better, worse or no change?

Open questions

What do you think has caused your fatigue?

What have you found hardest regarding your fatigue?

What do you think is likely to make it better?

FIGURE 4: Interview schedule.

The main limitation was the small number of patients recruited, though for a qualitative study, this is not particularly small. Several patients refused to take part as they were too tired or did not think they were tired enough to

be involved in study. Furthermore, we had to rely on nurses' initial screen of whether or not patients were fatigued before the researcher could approach them; this meant that we may have missed patients with fatigue.

We deliberately included patients at least one month after stroke, in order to explore the longer term impact of fatigue. We did not screen for depression, so it is possible that some of the participants' fatigue might have been explained, at least in part, by depression, though the ward staff screened for, and treated, depression as a routine aspect of the management of patients after stroke.

Previous work has shown that fatigue is still present for several years after the stroke [5]. Many of the factors that patients reported as being relevant to fatigue were specific to a ward environment, for example, boredom, noise, and ward regime with fixed times for meals and bedtimes. Thus, a similar mixed methods study needs to be performed in community-dwelling stroke survivors.

What are the directions for future research? The observation that fatigue seemed to start at the time of the stroke, and that post-stroke fatigue was different in phenomenology than prestroke fatigue is consistent with the concept that the brain lesion itself might trigger fatigue [12]. Thus, neuroimaging studies would be warranted to explore in more detail associations between fatigue and the site and size of the brain lesion. There are also other factors occurring at the time of the stroke that might trigger fatigue, for example, admission to hospital. The reported association between fatigue and poor sleep justifies larger observational studies seeking an association between fatigue and poor sleep. Given that sleep apnoea is sometimes a complication of stroke, studies to determine whether fatigue is associated with sleep apnoea would also be of interest. The reported association between exercise and improvements in fatigue is consistent with the findings of a previous qualitative study [15] and previous quantitative studies showing associations between fatigue and indices of reduced physical fitness [10, 13]. Graded exercise is effective for chronic fatigue syndrome [20] and might well be effective for post-stroke fatigue: this is an area where further research is needed.

Implications for Clinical Practice. Clinicians need to be aware that poor sleep and boredom are common problems for stroke survivors undergoing rehabilitation in hospital. Every effort should be made by ward staff to facilitate better sleep on stroke rehabilitation units and to provide activities to alleviate boredom.

5. Conclusions

This mixed methods interview study suggests that poststroke fatigue might be triggered by the stroke lesion itself or other events occurring at the time of stroke, for example, admission to hospital, and perhaps exacerbated by poor sleep and boredom. A complex intervention targeting these factors, and perhaps incorporating exercise, might plausibly improve fatigue after stroke, and should now be developed and tested.

Acknowledgments

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